

Wednesday 10 November 2004

Members present:

Dr Evan Harris Mr Robert Key Dr Brian Iddon Dr Desmond Turner

In the absence of the Chairman, Dr Desmond Turner was called to the Chair.

Witnesses: **Ms Marilyn Crawshaw**, Lecturer in Social Work and Research Fellow, University of York, **Ms Deborah Cullen**, Legal Group Co-ordinator, British Association for Adoption and Fostering, **Professor Eric Blyth**, Professor of Social Work, University of Huddersfield, **Dr Jim Monach**, Acting Chair of BICA and Honorary Research Fellow, University of Sheffield, and **Ms Sheila Pike**, Past Chair of BICA and Counsellor, Centre for Reproductive Medicine and Fertility, Sheffield Teaching Hospitals NHS Trust, examined.

Q901 Dr Turner: Good morning. You are very welcome. Your evidence towards this rather long- responsibility for children it is helping to bring into running inquiry will be extremely helpful, I am sure. being, it has that responsibility. Clearly we want to probe you on the social aspects of human reproductive facilities and the contribution towards thinking that social scientists can make. Perhaps, since you represent two bodies, PROGAR and BICA, you would have a spokesperson who would normally answer your questions, with help from your colleagues if required, because if we have five separate responses to each question it will take us all morning. Do you people advocate greater reproductive freedom? Do you think that counselling will reduce the likelihood that people will make poor choices in their reproductive therapies?

Ms Pike: I think counselling is a very beneficial process in relation to people making informed choices. It gives them an opportunity to consider the implications for themselves, for their partners, for their families, in an area that is completely confidential and quite separate from the clinical decision-making process, and I think that is vital.

Q902 Dr Turner: Does PROGAR have a view?

Professor Blyth: We would confirm that. Without taking up a lot of time, we do not have any disagreement on that particular point.

Ms Crawshaw: I think we would also want to add that the general climate, wherever treatment is being offered, is also very important. The counselling part is very important, but it is the whole experience and the general climate within which people are going for treatment within the clinic and within the wider society.

Q903 Dr Turner: We do not go through such angst over other areas of medical treatment. What is it, do you think, that makes human reproductive therapies so special that the involvement of medical technology needs additional restrictions on people trying to conceive that you would not place in any other area of medicine?

Professor Blyth: I think the bottom line is that the state is actually involved in helping people with the creation of a child. That would be our major view, that because of that, because of

the State's responsibility for children, it is helping to bring into being, it has that responsibility.

Dr Monach: In general, the enormous investment that couples bring to their treatment and bring to what they would describe as the need for a child. That, compounded with what Eric has just said, makes it requiring of the most careful support and scrutiny that I think is qualitatively quite different from many areas of medical health. Of course, the rapid advance of technology is one of the things on which we are focusing so much, and that simply compounds it.

Ms Cullen: Also there is the involvement of donor gametes and that adds a different part to the equation, in terms of both the state's involvement and the donor's involvement, and additional implications for the couple that are going to have the child.

Q904 DrHarris: More important than life and death treatment issues which are not regulated as much as this?

Ms Cullen: I would take Eric's point really, that it is the involvement of the state in actually helping a person to have a child. Death is going to happen anyway. It is not the intervention of the state that is going to bring that about.

Q905 Dr Turner: The interests of the state are not necessarily going to be the same as those of a couple are going for treatment desperate for a child. Where there is conflict, where do you think the balance should lie, between privacy and dignity of a couple wishing to conceive and the legitimate interest of the state where they do not coincide?

Professor Blyth: I think a judgment has to be made about the welfare of the child. Clearly the way in which the legislation is framed at the moment does impose a requirement to take account of the welfare of the child. Although people might think that it is problematic in the way that it is currently worded - and certainly we would hope this is something the Committee would look at—I think that is where the judgment has to be made, as it does in many other instances when the state is involved in family affairs where it might be seen that the state's interest, the child's interest, the interest of the parents might not coincide.

Q906 Dr Turner: Who should define the line?

Professor Blyth: Whoever has been given the responsibility to do that.

Q907 Dr Turner: Who do you think that should be? Should it be the HFEA's? Should it be Parliament? Should it be doctors?

Professor Blyth: Parliament should clearly set the harm. I do not see the HFEA getting involved in day-to-day instances, but whoever is legitimated by legislation and by the HFEA to carry out those sorts of responsibilities. Therefore, as it stands, it would be within the clinics.

Q908 Dr Turner: PROGAR, in your evidence you advocate a “holistic approach to the role of human reproductive technology in helping people to conceive and to nurture children.” Could you tell us what you mean by that. Are you suggesting that all infertility treatments should be regulated in the same way?

Professor Blyth: I think by that we mean that we are not purely talking about the medical and the technical aspects of infertility and assisted conception. If I could give an example, one might say that donor insemination, for example, is technically very simple, but, as we know, socially, emotionally, psychologically, in terms of relationships it can actually be very complex, particularly in the way in which children may be told or not about the nature of their conception. And obviously it is intergenerational, because people who have been conceived as a result of donor conception and other forms of assisted conception will inevitably grow up and may well have their own children as well, so we are talking about many years perhaps, down the track from the point at which a particular act of insemination or a particular technology was actually used. We are looking at it in terms of much wider implications but also longer term as well.

Q909 Dr Iddon: On UK birth certificates 14% do not have the father’s name entered. Obviously, in families where problems arise after birth, in those situations social services will deal with it. Set that against the fact that only one baby in 10,000 is born from donor sperm. Why do we need a welfare of the child provision?—which came late into this legislation in any case. Why do social workers feel strongly about that? We have to assume, of course, that the parents have been counselled prior to submitting themselves to the new technologies. Does that not seem rather strange, that we are so concerned about an unborn child in these circumstances?

Ms Crawshaw: One of the things I should make clear is that PROGAR is not only a British Association of Social Workers but a coalition of a number of different organisations. I guess one of the things we would say is that the notion of the welfare of the child in one sense is problematic—I think we would certainly feel the “need for a father” as the sub clause of it is problematic—but if we were to think about it in line with the way in which the state has chosen to protect children elsewhere, we would think in terms of “significant harm” rather than the welfare of the child, and that may be a way to consider going in terms of whether or not there is a way of excluding people from entering treatment where it is thought and there is good evidence to say that a child born to them may be at risk of significant harm. That then allows you to think differently about welfare of the children and welfare of the family unit that may be formed. If we are then allowed to think about welfare in terms of their wellbeing, as opposed to “significant harm”, which is a way of excluding people, then that allows us to think about the long-term family functioning of that unit and ways of minimising the risk of any difficulties that may arise within that family unit and maximising the chances of it working out well for them. That I think then opens up all sorts of other about preparing people for having a child who does not have a genetic relationship to them, for those people who may find difficulties at different stages of their family life as it unfolds. You start to separate the things out. Does that make sense?

Q910 Dr Iddon: A little sense but not complete sense. Would anybody else like to comment?

Ms Pike: You said, “We assume everyone will have been counselled” and of course not everyone is counselled. BICA is suggesting or proposing that there should be a requirement for everyone to attend an initial counselling consultation, really just to normalise the experience of counselling. There is a great deal of stigmatisation in relation to counselling: you are seen as not coping—and you are seen as not coping not just by the clinic but also, if you are in a couple relationship, by your partner. But if it is made a routine process, an opportunity for you to explore all these issues, as I mentioned earlier, independent of the clinical decision-making process, I think it is greatly advantageous.

Q911 Dr Iddon: BICA suggests that “interests and needs” would be better than “welfare of the child”, which suggests harm or risk to the child. How would you determine whether the interests and needs of a child to be born are being met, in effect?

Ms Pike: It is a very difficult area. Counsellors have traditionally been very keen to be seen as independent of the assessment process that is involved in welfare of the child, and I do believe it is a responsibility at present of the whole team. But, in terms of any future legislation, I would like to see clearer guidelines and I would like to see any assessment that is required made by people who are properly qualified to make that assessment. At present, I do not believe that is the case.

Dr Monach: I think it is important to make a very clear distinction between the sort of assessment we are talking about in this context and that we would be thinking of in adoption. We are not talking about setting a bar that is high in order to accommodate a child that is known, a child with established difficulties. We are simply trying to establish the most level of playing fields with most people who of course have their own child through ordinary means and do not get involved with counselling or anything else. We are very sympathetic to that view, which arises with couples who come to units seeking treatment. The important thing, as I think Sheila was saying, is that so often, because of stigma, because of the lack of acquaintance with what counselling is, it requires that first opportunity to meet with a counsellor to realise that they are not actually going to psychoanalyse, they are not going to dissect you, they are not going to be critical of you. Having that first opportunity, people then recognise just how beneficial it can be for them to think very carefully about these difficult consequences that will arise in having the gametes of another person in order to produce their own child, in particular, but it applies in different ways to other treatments as well.

Q912 Dr Iddon: More than half conceptions are unplanned. Some require only minimal intervention. Are these children’s interests and needs identical for the children you are so concerned about?

Dr Monach: When you say unplanned, you are talking about those who are not involved in treatment of any kind?

Q913 Dr Iddon: Yes.

Dr Monach: They are not identical, no, partly because of the technological intervention that is involved with assisted conception, partly because of the enormous stress which is engendered by a series of tests, a series of investigations. The impact on a couple's sexual relationship, on their personal relationships, their relationships with family and friends and so on, is huge when they are attempting to have a child of their own and require this sort of semi-public intervention, and other couples who, as who, as you say, maybe have an unplanned pregnancy and so on, do not have that kind of scrutiny. We still as a society take a pretty privatised view about sexual relationships, family relationships and so on—quite rightly, probably—but it is one that makes the experience of being a patient with assisted conception as a possibility one of feeling very vulnerable and very open to criticism, to attack, and to difficulties of all kinds. I think that makes them a very special population.

Q914 Dr Turner: May I put my colleague's question in a slightly more basic way: Are we not perhaps being a little too precious about this?

Ms Crawshaw: I think there is a danger of pathologizing the experience and I do not think any of us would want to suggest that it has to be a pathologized experience. I think one of the difficulties, particularly where donated gametes are used, is that it is still an area that does not get talked about very much. Most parents, if they are bringing up their children, have the opportunity to talk to others in a similar situation: "How are you managing this? What are you doing in relation to that?"—which of course they can do for whole aspects of their parenting, but for the part of their parenting which may be about: "And how do I handle talking about this . . ." where something may come up in relation to the genetic difference, a lot of those couples find that they do not have anybody they can talk to, unless they happen to have stumbled across DC Network or somewhere else. So part of the way in which we keep it as a relatively secret event I think does bring its own pressures. Of course there are not the services out there for people once they have left the hospital with their baby. There is not anywhere they can go unless they get into pretty major difficulties and have to start going to child welfare agencies or mental health services. We are looking at preventative stuff really.

Q915 Dr Harris: Bearing in mind we are discussing the welfare of the child, PROGAR suggest the welfare of the child should be paramount in line with other legislations. But other legislation applies to children after birth. How would you reconcile this with the health of the mother? In this respect should the an embryo have rights?

Ms Cullen: One of the difficulties of being a coalition is that different people have contributed different bits to this evidence and I think it is not feasible to make the welfare of an unborn child paramount. I do not think that is a line we would like to take. I think what Marilyn said earlier about maybe the current very vaguely worded test about "considering the welfare of the child" to "considering whether the child might be at risk of significant harm" would be a step forward and would actually allow people to concentrate on the real issues, rather than having what clearly is a completely idiosyncratic approach in different clinics to what "welfare of the child" means.²

Q916 Mr Key: The level of state intervention in this country is considerably higher than in most countries already, yet you are suggesting we need greater state intervention in what many people would regard as a private matter. Is there sufficient risk to welfare or indeed the interests and needs of children to justify the high level of intervention which you are suggesting is now appropriate? Where is the evidence for the risk?

Dr Monach: The evidence is in such studies that demonstrate, for example, that infertility and childlessness generate the second highest levels of anxiety and depression of all medical conditions. That would include cancer, MS and everything else amongst long-term medical conditions. It is very serious in that respect. The effects are long-lasting and so it is something to be considered from that point of view that contributes to the enormous load of depression which this country is still grappling with in its health services. That is one part of the answer. The other part is that I do not actually accept your premise that we are the most onerous in our approach to these issues in the world. There are other legislations where there are considerably stronger provisions now about the provision of counselling, for example, which is the area we were suggesting strengthening.

Q917 Mr Key: Can you give us an example of such a country, please?

Dr Monach: I believe that is now the case in Canada and Victoria in Australia. Perhaps others would like to pick up on other parts of your point

Ms Pike: In Canada the act has just recently been passed, but certainly everybody is expected to attend a counselling session. In Victoria everyone is expected to attend a minimum of two counselling sessions where donor-conception procedures are involved.

Q918 Mr Key: Why do you think that clinicians at infertility centres are incapable of counselling their patients?

Dr Monach: It is not a question of incapability. They are very capable of providing guidance and support, particularly guidance on medical matters; they are not capable of providing professional counselling, which is a very distinct skill which is learned through both academic and practical study. It is a problem of terminology. I know this is a semantic difficulty that counselling faces still in this country, but call it psychotherapy, call it counselling, as you will—it is called counselling in the legislation—they cannot provide that skilled assistance to people to explore their own feelings and their own approach to the issues that they face in a dispassionate way, enables them to come to decisions that are truly their own rather than ones that perhaps reflect loyalty to family, loyalty to the unit, loyalty to their doctor or outside our remit.

Professor Blyth: I can think of an entirely pragmatic angle to that as well: I think it would be very unlikely certainly that any clinician that I know of would have the time, let alone the necessary specific training, to provide in depth and continuing counselling, because, obviously, if they are doing that, they cannot be spending their time doing their main business, which is providing medical treatment.

Q919 Mr Key: I would like to pursue this question of anxiety that you mentioned. Where is the evidence that depression and anxiety about childlessness is ameliorated by compulsory counselling?

Dr Monach: Unfortunately, I must confess the research evidence is not strong—which may say something about the priorities of research councils. But there are studies. For instance, I was looking at a study the other day that came from Turkey, one from North America, one from Australia, all of which demonstrate that counselling had a very significant impact on the levels of anxiety and depression experienced after IVF treatment. But I do not pretend that it is the strongest of evidence. It needs a lot more work doing.

Q920 Mr Key: Thank you. Could I move on and comment on the fact that BICA wants to have fresh sperm hormone treatment within the act. Why not all treatments aimed at ameliorating infertility?

Ms Pike: I am not sure that was actually what was said but I apologise if I am mistaken.

Q921 Mr Key: I got the impression it was the point about fresh sperm and hormone treatment, because that is not currently covered.

Dr Monach: If I may comment, one of the anxieties about fresh sperm is the activities of some private bodies that are providing services that may be very dangerous and there seems to be no way of ensuring they are screened for HIV and other dangerous pathogens.

Q922 Mr Key: Do you have in mind a particular firm or company or organisation here?

Professor Blyth: I think the one that has been mentioned is called Man Not Included.

Ms Cullen: There is Man Not Included.

Q923 Mr Key: We have heard of them.

Dr Monach: Yes, I was hesitating.

Q924 Mr Key: There is no need to hesitate here.

Dr Monach: You may be protected; I might not be!

Q925 Mr Key: Let's move swiftly on then. Do you think the European Union Tissue Directive will bring safeguards for people undergoing treatment currently unregulated by the HFEA?

Dr Monach: My impression is it will, yes. It probably will but it is a scientific area that, to be honest, is outside our remit.

Mr Key: Thank you

Q926 Dr Harris: In paragraph 13 of your evidence you say that you “consider that any future revision of the HFE Act should have a wider remit in relation to regulation and incorporate such assisted conception procedures as . . . fresh sperm donation.” That is why we suggested that your evidence suggested that you were in favour of this. You base this on the view that it is “very dangerous”—which I think was the term you used.

Dr Monach: Yes.

Q927 Dr Harris: I am a little surprised that you think that using fresh sperm to conceive is very dangerous.

Dr Monach: I think I can see where you are going! It depends on the delivery system. I think that is my point.

Q928 Dr Harris: No, because you said the risk was of pathogens, and I am afraid it is an occupational hazard of having sex.

Dr Monach: Yes

Q929 Dr Harris: I am not sure why you feel that people who go to a clinic which has a reputation to protect, whatever you think of it, should be subject to greater control than those who go to a nightclub. Can you justify that?

Dr Monach: Excuse the levity. I was not meaning to make light of your point.

Q930 Dr Harris: That is all right.

Dr Monach: I was thinking of an agency such as we mentioned where somebody is making a business out of delivering fresh sperm for treatment purposes. I think obviously there are different situations that one was talking about, other clinics that are involved with this, but clearly the medical profession has taken a view that you cannot ethically be involved in treating with fresh sperm because you cannot screen for all these different conditions that we are concerned about. That is something for the medical profession to answer on the decisions taken about that, not for us, but certainly our view would be that it is appropriate that any treatment that is going to involve assisted conception ought to be brought within the scope of legislation where it goes beyond the bounds of something that is a personal relationship, where the state becomes involved. That is what we are arguing.

Q931 Dr Harris: At the same time you have just said you do not want to pathologize infertility. It seems to me that you are coming from two completely different directions. You do not want to pathologize it, you are concerned about stigma generally in this field.

Dr Monach: With respect, regulation does not pathologize necessarily. I find that a curious parallel.

Q932 Dr Harris: The basis on which you wish this to be regulated is pathogens, because of the danger—which is the term you used—and then you expanded that. So I think it does. I

think the basis upon which you wanted more regulation in this field, your initial reason for that, was because it was a dangerous thing pathologically.

Dr Monach: I am sorry, I think this is confusing a number of issues. We are most concerned about those areas of assisted conception that involve donated gametes. That is the area that we are particularly concerned that all the provisions about having counselling and the assessment that we have discussed ought to be strengthened from the position it is now. We wanted to go on to say that, because of the risks involved in some assisted conception, which is not regulated, we think it appropriate that people have the opportunity there, the active opportunity there, of counselling. We think all assisted conception treatments have an inherent—if you like—risk to their mental health as well as to their physical health. That is what I want brought in but I do not think that is pathologizing.

Dr Harris: We will agree to disagree. The risk to mental health and physical health is suggested as pathology. I think my colleague wants to comment.

Q933 Mr Key: Forgive me, if I may, Chairman. I find great difficulty with this approach. We are dealing with the practicalities of this, what is going to be the law. We know that up to 10% of children are not the offspring of their putative father. Do we have to provide counselling for this unofficial donor service that we know exists in society?

Professor Blyth: To refer to it as an unofficial donor service is a bit of a misrepresentation, if I may say so.

Q934 Mr Key: Why?

Professor Blyth: Because it is not a donor service, is it? That is not why people have entered into this relationship.

Q935 Mr Key: But in your terms it is, because it is the donation of gametes.

Professor Blyth: It comes back to a point I made at the very beginning, that, if people go to their nightclub and do whatever people do at nightclubs, the state has no responsibility for that. We are not saying that because we are taking a certain line in relation to people who are seeking to conceive through assisted conception units, therefore the rest of the population should be subjected to something. That is effectively a police state really. We are certainly not saying that.

Q936 Dr Harris: I understand that point. So using fresh sperm is not a problem of the state. Are you not having a circular argument, because you want to involve the state by regulating it and then say that because the state is involved therefore there needs to be regulation and procedures. It seems to me that you create the situation that then sends some work your way—and I am talking to the counsellors here.

Professor Blyth: What has happened in relation to . . . I will not use the name of the organisation again, just in case.

Q937 Dr Harris: Feel free. I do not think it is a problem.

Professor Blyth: The internet sperm banks were obviously set up to get round the regulation in the Act. There was no other purpose in setting up, other than to by-pass legislation, and I do not think anybody can regard that as satisfactory. I do think there is a qualitative difference between somebody having a good night at a nightclub, where presumably the intention is not to conceive—I guess very much the opposite—as opposed to going to an organisation like Man Not Included where the specific objective is to have sperm from who knows where and to conceive a child. I think that is a qualitative difference.

Q938 Dr Harris: I have spoken to people who say they would rather use these fresh sperm services because there is some screening, which it is far more difficult to get from a stranger encounter, and, in fact, that they might consider using these services because of the change of legislation that will force them otherwise to have a donor that is identified, which they do not want. So there are other reasons rather than simply getting round regulation, although perhaps the second one is that. I want to raise another issue with you, the suggestion that BICA think that counselling should be made mandatory for assisted reproduction. We have covered this already, but clearly you must recognise that that you have an interest, because it is creating more work for counsellors and therefore more members for you and therefore a bigger organisation.

Ms Pike: I think that is a cynical attitude.

Q939 Dr Harris: How do you solve the problem that here is an association of councillors saying: We want to force people to have counselling whether or not they need it and whether or not they want it in this field specifically.

Ms Pike: Perhaps I could start by saying that I think that is a rather cynical view of counsellors and their profession if you think we would generate business for ourselves in this way. I would strongly refute that.

Q940 Dr Harris: Do counsellors counsel for free?

Ms Pike: No, they do not.

Q941 Dr Harris: So I think it is realistic, not cynical, but, again, we may have to—

Ms Pike: Disagree on that.

Q942 Dr Harris: Yes, indeed.

Ms Pike: Perhaps the term “mandatory counselling” is not the best way to describe it. I do not believe that you can impose counselling on anybody but I do believe that you can offer a realistic opportunity to people. At the moment the opportunity that is provided varies from centre to centre and I think it is important that people have an opportunity to attend an initial counselling consultation in order that—

Q943 Dr Harris: How is that different, though? Because the current section 13, paragraph 6, I am told in this briefing, says that, “A woman shall not be provided with any treatment services . . . unless the woman being treated and, where she is being treated together with a man, the man have been given a suitable opportunity to receive proper counselling about the implications of taking the proposed steps . . .” That is what you just said, they should have the opportunity.

Ms Pike: No. It is how you define that suitable opportunity. A suitable opportunity might just be a consultant mentioning, “You could go along to counselling, and here is your next appointment.” Or perhaps they are given written information about the counsellor. It is very much the way the counselling is described and delivered within each individual unit that will impact on the take-up of counselling. I do believe that, because there is still a stigma attached to counselling, there is a fear perhaps that people assume—and I think I have said this before—that they will be seen as not coping if they attend the counsellor. I believe that if that is made a routine procedure, just as routine as an initial clinical consultation, that they attend the counsellor and they are able to find out for themselves what is involved in counselling, it demystifies counselling, it allows them to identify future counselling needs. To be sure, if they feel that counselling is not for them, there is no more requirement for them to go any further with it.

Q944 Dr Harris: You said earlier that you accepted, Dr Monach, that the evidence base that the efficacy of counselling in these circumstances was not strong.

Dr Monach: In these. The evidence for the efficacy and effectiveness of counselling in a range of other circumstances is strong.

Q945 Dr Harris: But in these circumstances.

Dr Monach: Yes. I am being pedantic.

Q946 Dr Harris: It could be argued that it is reasonable for government, before we impose a mandatory requirement in these days of regulatory burdens and all this, to ask for there to be evidence.

Dr Monach: Yes.

Q947 Dr Harris: You said there was not evidence because of these damn research councils—and as a committee obviously we hear this all the time—but is it not incumbent on the

counselling industry to provide strong evidence, and, if necessary, if it is so critical, to fund it themselves.

Dr Monach: Yes. I do not entirely disagree with what you say. I think it is very important that counsellors themselves develop a better research base than there is at the moment and it is partly because of timing: 14 years still makes infertility counselling quite a young profession and a lot of emphasis needs to come from them. But, could I just come back to the other point, because I think you made an excellent point when you read out what the act says about a suitable opportunity. In a sense, our argument is not so much with the act, it is more with the code of practice within the HFEA, because I too do not see any reason why one should not interpret the meaning of what you read out as being precisely what we are arguing for and what Sheila described. It is because the code of practice does not interpret in that way, and clinics are quite happy to say, "Well, a suitable opportunity just means that we have a notice on the clinical wall." From where we stand, a suitable opportunity would be exactly what you describe and we have argued for.

Q948 Dr Iddon: What percentage of people undergoing the new technologies seek, or are advised and therefore seek, counselling? Is it very tiny?

Dr Monach: It varies enormously, as Sheila said. We do not have any formal figures, but, wearing another hat, I am an inspector for the HFEA, and going around you look at the figures that are being generated and it can go from anything like 2 and 3% right up to 40%, and it entirely depends on the attitude and the practices of the clinic. If those in the clinic are keen, they are motivated, they understand what the counsellor offers, they are enthusiastic and they do not just stick a notice on the wall, then a lot of people will take up the opportunity. It is back to the point we were making earlier really, that unfortunately the perception is still that counselling is a demonstration of weakness and not a strength.

Q949 Dr Harris: If I may come back to this evidence point.

Dr Monach: Evidence about . . . ?

Q950 Dr Harris: Evidence about the efficacy of counselling, mandatory or otherwise. Given that the HFEA, on issues around egg giving, say, "Where is the evidence that this provides better results in their evidence base?" it would not be unreasonable of us, surely, to recommend that we do not go down this "more counselling" path and say, "Come back in ten years when you have the evidence that it is useful" because it is a burden.

Dr Monach: I can say to you quite conclusively that there are lots and lots of studies now that say that the increase in depression and anxiety amongst childless couples is very significant, is more significant than most other long-term medical conditions. You can say, on the one hand, that is clearly demonstrated, and on the other hand you can say that counselling is now very well established as effective as a first-line intervention for people with anxiety and depression. Those two are quite indisputable in the literature now and therefore I think it is quite possible to put those two together, even though not much work has been done on the infertility-driven depression and the counselling.

Q951 Dr Harris: I am not against counselling, I am just saying that, in other areas of mental health, unless they fall under the act they do not have mandatory treatment. I am surprised that you are arguing that in this particular area of—

Dr Monach: Sorry, your question was about the force parents who are using regulated gamete literature.

Q952 Dr Harris: —mild to moderate mental health problems (that is, depression based on infertility— given that you accept the stigma, which, if you force people to go down something that stigmatises, for better or worse might be a barrier for treatment) there should be mandatory treatment

Dr Monach: No.

Ms Pike: No. I think you are pathologizing now. We are not talking about mandatory treatment at all. I think people should be required to attend an initial consultation, an initial counselling consultation.

Q953 Dr Harris: All right. I am going to move on to the issue of donor anonymity and ask again what the evidence was and what studies you are aware were done by the HFEA that showed that this would be in the interests or the welfare of the child produced by donated gametes

Professor Blyth: We need to recognise that the decision about anonymity has been made by government already, so to some extent we are talking after the horse has bolted, so to speak. Given that proviso, there is certainly increasing evidence, based on a number of small-scale studies—and I guess I am likely to fall into the same difficulties as colleagues have earlier in relation to convincing you that there is sufficient empirical evidence. The whole problem about getting empirical evidence in relation to anonymity is that, because the practice has been characterised by secrecy and anonymity, that has presented a very major barrier in undertaking any research anyway. With that proviso, the information that we do have is from a number of studies in this country, and in the United States, which indicate that people who have learned about their origins, from a variety of ways, sometimes in adulthood, sometimes by accident, sometimes as a result of family disagreement, have actually experienced extreme psychological discomfort because that information had been withheld from them previously.

Q954 Dr Harris: That is the point. Because it seems from my understanding of the evidence, that there is at least a series of cases, which one might describe as anecdotal, of people who feel they have been damaged by the secrecy—by the fact that they have not been told—as well as—but mainly that — not being able then to identify, somewhere out there, their fathers,

say, in the case of donated male gametes. There is some evidence I have also seen that ending donor anonymity makes it more likely that parents will not tell the child of the fact of their gamete-donated origins. That is therefore more secrecy and runs the risk of the secrecy being discovered. Would it not be logical, on that basis, to force parents who are using regulated gamete donation, where there is no longer anonymity, to tell the children of the fact at the appropriate age so that they can then trace their parents?

Professor Blyth: I am sorry, I got a bit lost in terms of the actual question. One of the points you said was that you were aware of some evidence that said that parents were less likely to tell their children. I would be interested to know what that is because I have certainly not seen that.

Q955 Dr Harris: If people who have been asked, “Why do you not tell the child?” say, “Well, we don’t want them to go out and look for the other parent,” that is understandable

Professor Blyth: But the evidence that is available is very much the other way. The evidence that is available is that parents are reluctant to tell their children because of the very little information they have about donors, both in terms of non-identifying information that they have been given themselves and particularly if they do not know the identity of the donor. That comes through time and time again, that one of the reasons why parents do not tell is because they are opening a can of worms, because they will not be able to answer the follow-up questions these children will have—which will be information about the donor and information about the identity. Anticipating the next session, there is a very recent piece of research, of which Professor Golombok is a co-author,³ which shows quite clearly that parents who have told their children report far fewer difficulties in terms of their relationship with their children and their children’s development than parents who have actually not told their children. So we have the evidence—

Q956 Dr Harris: I understand what you are saying. I would be interested to see the evidence, so feel free to send it in. Should we not now, because of all these benefits of this openness, just tell the children? You do not have to get the parents to do it; you just tell the parents that the register will contact the children and tell them at the age of 16 or 18. Win, win, win.

Professor Blyth: No, I have not said that at all. I think that is a gross interference in terms of parents’ responsibilities towards their children.

Q957 Dr Harris: But children have rights.

Professor Blyth: Parents ought to be strongly advised that the evidence suggests that it is better if children are told. You will have heard this from organisations like DC Network.

Q958 Dr Harris: I am not arguing with you, I am just asking why you do not take the next natural step.

Professor Blyth: It is not a natural step.

Q959 Dr Harris: Which is to tell them and then give them mandatory facts.

Professor Blyth: With all due respect, that is not a natural step for the state then to disregard parental wishes and say, “Well, we are going to find some way of telling these children anyway.”

Q960 Dr Harris: If parents want anonymous donation, do you think the state should disregard parental wishes in those circumstances, on the basis of what is, at best, shaky evidence.

Professor Blyth: Yes, I do. I do not think – as indeed the Government have accepted—that continuing the availability of anonymous donation should be permitted, because, for all the reasons we know about, that is not conducive to children’s welfare.

Ms Crawshaw: I would want to come in to say, on contacting children at the age of 16 or 18, that I would be more concerned about it from the point of view of that individual: if they suddenly get a letter out of the blue—or however you are suggesting it — when you do not know whether or not they do know, because obviously one of the concerns we have is about unplanned or accidental disclosure of information at a later age anyway. I think it would add into something we are concerned about, that we know from the adoption field—which is not the same, but which is the closest professional experience that we have — of the need for intermediary services at the point at which people may be receiving information from the register or elsewhere about their donor. I think that is very difficult for people to manage by themselves. We know from adoption that it is very helpful to have intermediary services.⁴ One of our concerns would be if that remains as an offer at that stage as well, rather than that the services are there and provided and people should have them.

Q961 Dr Harris: My last question is about the consultation that is forthcoming on payment for gamete donation. What would you want to from that? Do you think the issue of the ending of anonymity should have a bearing on the question of the level of expenses that are paid?

Professor Blyth: In terms of expenses, our view would be that all legitimate expenses should be reimbursed. We certainly would not want to move to a situation that then might be seen as the commodification of gametes or embryos. We would want to ensure that that distinction continues. That has been a hallmark of the provision in this country. Reimbursement of legitimate expenses.

Q962 Dr Harris: If the ending of anonymity causes a real drop in the supply of donated eggs—and that has been postulated, and, indeed, some people are telling me that has already happened—do we just say, “Well, people will not get treated” or do we say, “Let’s raise the level of expenses”—or be honest and call it “payment”—in order that, again, it is a win a win: someone gets the money/someone gets treated.

Professor Blyth: I can understand why you are commenting in that sort of way. Our point is that we would see the reimbursement of legitimate and reasonable expenses. I take your point entirely, and one could move into the American system where you pay “the market rate”, but, albeit that it may impact on supply, we are certainly not into recommending paying the highest bidder.

Ms Pike: I would certainly agree with Eric and see payment as a commodification and, as such, a very unethical approach. I do not see how you can remove anonymity and say that we are doing this for ethical reasons and then try to solve the consequences in such an unethical way.

Dr Harris: You pay the doctors, you pay the counsellors, you pay the cleaners—everyone gets paid except the donor.

Q963 Mr Key: On the question of parents telling children how they were conceived, we know that the majority of parents who are seeking to access treatment with donor gametes say they will tell their children because they perceive that is what the counsellor wants to hear; whereas we know that the overall majority—round about 85%—do not in fact tell.

Ms Crawshaw: I do not think we do know. I think that is one of the great difficulties in the whole area where you are trying to influence policy and practice on the basis of quite a lot of unknowns. Certainly, anecdotally, if you talk with people in clinics, even over the last five years I think there has been a very significant change in the numbers of people coming forward for treatment who are saying, “We intend to tell,” and I do not think that is just because they think that is what they should say. I think there really has been quite a change and it is more them thinking about “How do we go about telling?” because that is a complex area.

Q964 Mr Key: Finally, interestingly PROGAR have challenged the legitimacy of this Select Committee, saying that because we do not have MPs from all four countries of the United Kingdom therefore it is a democratic deficit. May I gently point out that PROGAR’s

representatives do not either come from all parts of the country. What is the point you are trying to make here?

Ms Cullen: I do not think it is a real point.

Q965 Mr Key: Why make it then?

Ms Cullen: We are in some embarrassment about that in terms of the three of us here not having ourselves written the evidence.

Q966 Mr Key: There must have been a deep reason why you thought it was a point worth making, even though it was perhaps made in jest.

Ms Cullen: No, it was not made in jest, but there is a point about the complication of some areas being half-devolved, like the regulations which dictate at what age a person born as a result of surrogacy or through donor-assisted conception will access the information, because the Scottish one is paralleled on the Scottish adoption law and the English one is posited on the English adoption law. I do not think it is actually a huge issue, as long as there is an awareness within the HFEA (or whatever body might replace it) of the distinctions and the guidance that gets issued to clinics and to users, that there is not uniformity between the four countries, and the differences will get greater because things will get more different probably in Wales as well.⁵

Mr Key: Thank you. I think that is a very sensible point.

Q967 Dr Iddon: Finally, if people get frustrated with the struggles against quite tight regulation in this country—and after all we are ahead of the field—they will just pack their bags and go abroad. What do we do about that? Do you think that is important, reproductive tourism?

Ms Crawshaw: It is a very real issue and I do not think we would pretend to have any answers around it. We are hearing of clinics that are setting up links with clinics in Europe and then saying to people, “You can go and get your treatment there and get round the anonymity, if that is what you want to do.” It is extremely difficult. I do not know what the solution would be. In adoption we had a similar problem of overseas adoption and learned some very hard lessons from it⁶ with some children and families who really got into some quite deep difficulties. I am not suggesting that would necessarily happen, because we do not know, but I think it is a concern.

Q968 Dr Iddon: Should we legislate?

Dr Monach: We already do in terms of importing and exporting gametes themselves. But, in terms of the people going abroad for treatment, I think that would be very difficult. That would be our view. It would take us into a really major set of obstacles really.

Q969 Dr Iddon: You have no answer to the parliamentarians?

Professor Blyth: It is difficult, even as parliamentarians. Well, I say “even”—I mean, from where I am sitting you are far more powerful people than I am in certainly trying to change things, but, even so, we do have to recognise the limits of these.

You talk about reproductive tourism in the sense of thinking of people from the UK going elsewhere, but we also need to think that we currently have a very liberal system compared even to many western European countries and the UK is also the destination of a lot of people. I do not know if anybody does know the figures, but people do come into the UK for treatment because it is not permitted in their own countries. I am thinking of countries that do not allow egg donation, for example, that do not allow embryo donation, countries where they are far more restrictive on sexual orientation and marital status in terms of accessing particular assisted conception procedures. I should not go so far as saying the UK is a magnet to people in those sorts of situations but we know there are a lot of people who come to the UK for that as well. I do think it is a difficult issue and probably there are elements of that that no individual country can successfully legislate for. We just have to accept that.

Dr Iddon: It sounds like a debate for another day.

Dr Turner: On that note of controversy we will stop this session. Thank you very much for your contributions.

1 *Note by the witness:* “Significant Harm” is the test applied by s.31 Children Act 1989; the court must be satisfied that a child is suffering, or is likely to suffer, such harm before it can make an order interfering with the parents’ parental responsibility.

2 *Note by the witness:* For the avoidance of doubt, we would wish to confirm that we are not suggesting that the welfare of an unborn child should be paramount

3. *Note by the witness:* Lycett, E, Daniels, K, Curson, R, and Golombok, S, (2004). “Offspring created as a result of donor insemination: a study of family relationships, child adjustment and disclosure”, *Fertility and Sterility*, 82(1), 179–179

Comment [EDB1]: This is a typo in the original document

4 *Note by the witness:* See, for example, Section 98 Adoption and Children Act 2002.

5 *Note by the witness:* PROGAR would like formally to withdraw its challenge to the legitimacy of the Select Committee. The point that it wishes to make in relation to the four countries of the UK is that which was made by Ms Cullen.

6 *Note by the witness:* In the field of adoption much has been done to try and achieve safeguards at an international level, in particular the 1993 Hague Convention on Protection of Children and co-operation in Respect of Intercountry Adoption, ratified by the UK in 2003.